

**STATEMENT OF SUZANNE MINTZ
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SUBCOMMITTEE ON AGING OF
THE SENATE HEALTH, EDUCATION, LABOR AND PENSIONS COMMITTEE
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Mr. Chairman, members of the Committee thank you for this opportunity to speak in support of reauthorization of the Older Americans Act, and in particular the National Family Caregiver Support Program. My name is Suzanne Mintz, and I am the President and Co-founder of the National Family Caregivers Association (NFCA), and a caregiver myself for more than two decades for my husband who has multiple sclerosis.

NFCA's mission is empower family caregivers to take actions that will improve their life and the life of their loved one by providing them with education, support, and a public voice. NFCA reach across the boundaries of differing diagnoses, different relationships and different life stages to address the common concerns of all family caregivers. NFCA is located in Kensington, MD.

Our members care for spouses, children, aging parents, siblings, friends and others. The majority of our members care for seniors and they tend to be "heavy duty" caregivers, meaning they are providing hands-on care on a daily basis, helping loved ones, dress, bath, toilet etc. The stories they share with us paint a picture of isolation, a lack of information and understanding of available resources, a need for respite, and financial assistance.

I would like to share a story that we received some years ago from a woman right here in Potomac, MD, Sheue Yann Chen. To this day it is imprinted on my mind.

My husband is now 66 years old. He has a ... progressing debilitating neurological disease, which has no treatment and no cure. Since the diagnosis of his disease, I have been watching his slow death day by day.

He now can no longer talk, walk, stand or feed himself. He is totally incontinent and needs full time assistance for daily living. I receive no financial help and work full time to support his full time home care. I am now 62 years old and shoulder the entire household responsibility, from cooking, cleaning, shopping, learning to fix faucet leaks, mowing the lawn and shoveling the snow. I am over-worked and worn out. Because of his illness, we have no social life ... Since his illness, many friends that we used to have abandoned us. I feel very alone, constantly worrying about my husband's health. Life has been a struggle for me.

... what can help me is to have a resource center which has names that I can call for finding a dependable workman to install a wheelchair ramp or fixing other household problems (e.g. leaking roof, etc.), ...assistance

for transportation when my husband needs to go to see the doctor, financial assistance for home care. At the minimum, financial assistance for a two-week respite leave would be extremely helpful.

The National Family Caregiver Support Program, a part of the Older Americans Act, began providing services to family caregivers of the elderly and elderly people caring for children in 2002. Since that time it has helped over 25,000,000 people like Mrs. Chenn across the country.

- ❑ Over 1.5 million caregivers have received help in accessing services.
- ❑ Almost 22 million have received information about caring for their loved one.
- ❑ Over 814,000 have received counseling, become part of a support group, or learned new caregiving skills.
- ❑ Almost one half million caregivers have gotten some of the respite they desperately require and
- ❑ Approximately 350,000 caregivers have gotten supplemental services to help them meet very specific and immediate needs.

Research has shown over and over again that family caregivers put their own health at risk as they assist their loved one. Family caregivers are more prone to depression than the rest of the population, among some subpopulations as much as six times as high. Research has shown that the stress of family caregiving can trigger the advent of chronic illnesses, and in extreme situations increase mortality rates.

In my own state of Maryland just under 45,000 people have been served by the National Family Caregivers Support Program since its inception for a cost of \$2,165,437. That's \$48 and change per caregiver - about the cost of a dozen lattes. That is a very small investment indeed in the health and well being of those Americans who are providing care to the most vulnerable of our citizens. It is a small investment in keeping family caregivers on the job. After all when a family caregiver becomes sick and cannot provide care, society pays the price.

As impressive as some of these numbers sound, we can not lose site of the fact that there are more than 44 million people who provide care to a loved one over the age of fifty and the numbers of caregivers served that I have quoted represent services over a three-year period. There are so many family caregivers that have not had the opportunity to be served, either because sufficient funds were not available or because they were not even eligible.

Family caregivers are the mainstay of our nation's long-term care system. Family caregivers strive, often beyond the point when it is beneficial to all concerned, to keep their loved one at home. In times of tight budget constraints supporting family caregivers is sound fiscal policy. That is why it is troubling that the Administration on Aging's budget request seeks fewer funds for the National Family Caregiver Support Program in fiscal 2007 than it currently receives, approximately \$2 million less, \$154 million for '07 versus \$156 million in 06.

I know that there are new initiatives being proposed, that will if implemented, provide some services to caregiving families. The budget calls for the creation of a new program of competitive grants, Choices for Independence, a \$28 million initiative that will provide a flexible care plan of services for eligible individuals and therefore in the process support their family caregivers as well. I know that there are funds allocated for the Aging and Disability Resource Center program that began in 2003 to serve as single entry access points, but these are all small competitive grant programs that will serve only a small number of people and only indirectly support family caregivers.

The first of the baby boomers turned 60 last month. Our aging population is on the rise and with it the number of people who will need long-term care. People over 85 are the fastest growing segment of the population and over half of them need help with personal care. I am all for more flexible and integrated programs that address the totality of a person's needs, and providing services for a person with a chronic illness or disability does indirectly help their family caregiver, but it doesn't address the very specific needs of the caregiver directly, only the National Family Caregiver Support Program does that.

I know that money for programs to support needy Americans is very tight right now to say the least, but I fear that the proposed direction of the fiscal 2007 AOA budget will leave even more family caregivers fending for themselves than has already been the case.

The implementation of the National Family Caregiver Support program in 2000 was a milestone in this country's recognition of the critical role that family caregivers play in our healthcare and social support system. Reducing its allocation sends a message that the work of family caregiving – upon which our nation relies so heavily – is not as valuable as once thought. That is a step backwards and one that as a family caregiver advocate I must decry.

Hubert Humphrey, for whom the headquarters building of the Department of Health and Human Services is named, once said "A society is judged by how it treats its most vulnerable citizens". What can we say about America's concern for its most vulnerable citizens if we cut back on the one and only program designed to support those they rely on so heavily. Over two thirds of all seniors needing care get it solely from family and friends. It is imperative that we recognize the enormity of the work that family caregivers do in support of the elderly and the negative impact it has on their own wellbeing. By cutting the few social support services that exist we are only adding to the pool of family caregivers who will require more expensive services from our healthcare system, today and tomorrow. I implore you to consider at least funding the National Family Caregiver Support Program at current levels, if not adding to them.